Anonymised Register V1.0 User Guide

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1. Modification History

DATE	MODIFICATION	AUTHOR
26/04/2010	Version 1.0	David Moysen

2. Scope

Document Audience: Researchers/Interested Parties

Review Frequency: ad-hoc

3. Introduction

3.1. The Register

Information about In Vitro Fertilisation (IVF) and Donor Insemination (DI) treatment in the UK has been collected by the HFEA since it was established (1 August 1991). Since that date, clinics have been required by law to report details of the treatments they carry out to the HFEA. Consequently the HFEA maintains the largest database of infertility treatments in the world.

The information that we currently collect is detailed here:

http://www.hfea.gov.uk/fertility-clinic-forms.html

Whilst these are examples of paper forms, the actual data returned to us is made electronically using our Electronic Data Interchange (EDI) system and we currently process about a quarter of a million forms per year. This information is then held on the HFEA Register.

However, the original incarnation of the HFE Act made it impossible for the HFEA to share this information with anybody outside of the Authority. Any analyses of the information we hold had to be made internally and for researchers et. al. Specific enquiries about Register data were answered through the Freedom of Information Act. The legislation changed in October of 2009 to allow access to the Register for researchers, about which more information be obtained here:

http://www.hfea.gov.uk/5447.html

3.2. Anonymised Data

The anonymised Register will, we hope, allow a broader audience to view, analyse and interpret the information that we hold. We have chosen what we feel is a useful subset of the Register and applied a broad range of techniques to ensure that none of the information contained is identifiable.

This is the initial release of the anonymised register and we will update the dataset in line with the publication of out Choose a Fertility Clinic data – every three months. It is also our intention to enhance this data over time and we would welcome any suggestions for improvement – please send an email to informationsupport@hfea.gov.uk

3.3. Data Quality

The types of forms, the information that we have collected and the method of data collection have changed over the years since the inception of the HFEA. Up until 2006 information was returned to the HFEA on paper forms which were then keyed into the Register which led to transcription errors. The forms that we used to collect information also changed several time so some of the data that we hold is not present across all the years of the Register.

The HFEA now runs rigorous data checking routines over the information received and requires clinics to correct any erroneous returns. We also ensure that the information that we have a statutory obligation to maintain is correct from 1991 to date. As such the end-user of this anonymised register may encounter records that appear incongruous or impossible to reconcile.

4. Using the Anonymised Register

4.1. Opening the data

The anonymised register in this release (1.0) is supplied as character delimited data, the delimiter used being the pipe '|' character. There are 20 files that make up the dataset:

1991-HFEA-AR-V1.0.psv

...

2009- HFEA-AR-V1.0.psv

And

HFEA-AR-V1.0.psv

The latter file contains information from all years of the Register and the others contain the same divided into more manageable annual chunks.

Instructions on how to import the information into any particular application is beyond the scope of this document.

4.2. Using the Data

This information covers cycles in the period 01-01-1991 to 31-03-2009.

This dataset contains 87 fields of data across 835,000 rows of cycle data.

The content of each field is described in more detail in section **Error! eference source not found.** and is generally self explanatory

4.3. Data Types

Number	Numeric Value
Bit	Simple Yes/No Type
Text	Alphanumeric data

4.4. Notes on Data Values

Text Fields can include multiple pieces of information for example different types type of stimulation used in a cycle. They can also include numerical data that has been split in to bands e.g. patient age at treatment.

The value NULL will also be seen frequently in fields. This indicates that a value for this field has not been captured for the specific cycle.

4.5. Data Dictionary

Field Name	Type	Description
Patient Age at Treatment	**Text**	This patient's age at treatment, banded as follows: 18-34,35-37,38-39,40-42,43-44,45-50
Date patient started trying to become pregnant OR date of last Pregnancy	**Number**	The number of years ago that patient started trying to become pregnant or years since last pregnancy
Total Number of Previous IVF cycles	**Number**	How many cycles of IVF the patient has previously had
Total number of previous pregnancies	**Number**	How many time the patient has previously been pregnant
Total number of IVF pregnancies	**Number**	How many times the patient has been pregnant through the use of IVF
Total number of Previous live births - naturally conceived or through IVF	**Number**	How many live births the patient has had
Type Infertility - Female Primary	**Bit**	1 if the main cause of infertility is due to the patient, 0 otherwise
Type of Infertility - Female Secondary	**Bit**	1 if the secondary cause of infertility is due to the patient, 0 otherwise
Type of Infertility - Male Primary	**Bit**	1 if the main cause of infertility is due to the partner, 0 otherwise
Type Infertility - Male Secondary	**Bit**	1 if the secondary cause of infertility is due to the partner, 0 otherwise

Type of Infertility - Couple Primary	**Bit**	1 if the main cause of infertility is due to the patient/partner problem, 0 otherwise
Type of Infertility - Couple Secondary	**Bit**	1 if the secondary cause of infertility is due to the patient/partner problem, 0 otherwise
Cause of Infertility - Tubal disease	**Bit**	1 if the primary cause of infertility is tubal disease, 0 otherwise.
Cause of Infertility - Ovulatory Disorder	**Bit**	1 if the cause of infertility is Ovulatory disorder, 0 otherwise.
Cause of Infertility - Male Factor	**Bit**	1 if the cause of infertility is a male factor , 0 otherwise.
Cause of Infertility - Patient Unexplained	**Bit**	1 if the cause of infertility is an unexplained patient factor, 0 otherwise
Cause of Infertility - Endometriosis	**Bit**	1 if the cause of infertility is endometriosis, 0 otherwise
Cause of Infertility - Cervical factors	**Bit**	1 if the cause of infertility is cervical factors, 0 otherwise
Cause of Infertility - Female Factors	**Bit**	1 if the cause of infertility is an unexplained female factor, 0 otherwise
Cause of Infertility - Partner Sperm Concentration	**Bit**	1 if the cause of infertility is due to partner sperm concentration, 0 otherwise
Cause of Infertility - Partner Sperm Morphology	**Bit**	1 if the cause of infertility is due to partner sperm morphology, 0 otherwise
Cause of Infertility - Partner Sperm Motility	**Bit**	1 if the cause of infertility is due to partner sperm motility, 0 otherwise
Cause of Infertility - Partner Sperm Immunity	**Bit**	1 if the cause of infertility is due to partner sperm immunity, 0 otherwise
Main Reason for Producing Embryos Storing Eggs	**Text**	A comma separated list of the main reason for this cycle which can include: Treatment Now ,For Donation ,For Storing Eggs, For Research
Stimulation used	**Bit**	1 if this was a stimulated cycle, 0 if not
Type of Ovulation Induction	**Text**	A comma separated list of the types of stimulation used
Egg Donor Age at Registration	**Text**	If donor eggs were used, the donor's age at registration banded as follows: <=20,21-25,26-30,31-35
Sperm Donor Age at Registration	**Text**	If donor sperm was used, the donor's age at registration banded as follows: <=20,21-25,26-30,31-35,36-40,41-45,>45
Donated embryo	**Bit**	1 if this cycle used a donated embryo, 0 otherwise
Patient acting as Surrogate	**Bit**	1 if the patient was acting as a surrogate in this cycle, 0 otherwise.
Treatment Type - IVF or DI	**Text**	Either IVF or DI

Specific Treatment Type	**Text**	A comma separated list of specific treatment types used in this cycle - see http://www.hfea.gov.uk/glossary.html for an explanation of the terms
PGD	**Bit**	1 if this cycle involved the use of preimplantation genetic diagnosis/screening, 0 if not
Elective Single Embryo Transfer	**Bit**	1 if this cycle involved the deliberate use of only one embryo
Egg Source	**Text**	Indicates whether the eggs used in this cycle came from the Patient or a donor
Sperm From	**Text**	Indicates whether the sperm used in this cycle came from the Patient, Donor
Fresh Cycle	**Bit**	1 if this cycle used fresh embryos
Frozen Cycle	**Bit**	1 if this cycle used frozen embryos
Eggs Thawed	**Number**	If this cycle used frozen eggs, the number of eggs thawed
Fresh Eggs Collected	**Number**	The number of eggs collected in this cycle
Fresh Eggs Stored	**Number**	The number of eggs collected in this cycle and subsequently frozen
Total Eggs Mixed	**Number**	The number of eggs mixed with sperm
Eggs Mixed With Partner Sperm	**Number**	The number of eggs mixed with sperm from the partner
Eggs Mixed With Donor sperm	**Number**	The number of eggs mixed with sperm from a donor
Total Embryos Created	**Number**	The total number of embryos created in this cycle
Eggs Micro-injected	**Number**	The number of eggs that were injected with sperm e.g. By ICSI
Embryos from Eggs Micro-injected	**Number**	The number of embryos that developed from injected eggs
Total Embryos Thawed	**Number**	If this was a frozen cycle, the total number of embryos that were thawed
Embryos Transferred	**Number**	The number of embryos transferred into the patient in this cycle
Embryos Transferred from Eggs Micro-injected	**Number**	The number of embryos transferred into the patient in this cycle that were created by injecting sperm
Embryos Stored For Use By Patient	**Number**	The number of embryos that were created in this cycle and then frozen for subsequent use by the patient.
Embryos (from Eggs Micro-injected) Stored For Use By Patient	**Number**	The number of embryos that were created in this cycle by injecting sperm and then frozen for subsequent use by the patient.
Date of Egg Collection	**Number**	0 if eggs were collected, NULL if no eggs were collected
Date of Egg Thawing	**Number**	
Date of Egg Mixing	**Number**	
Date of Embryo Thawing	**Number**	

Date of Embryo Transfer	**Number**	
Year of Treatment	**Date**	The year in which this cycle took place
Live Birth Occurrence	**Bit**	1 if there was 1 or more live births as a result of this cycle, 0 if not
Number of Live Births	**Number**	The number of live births as a result of this cycle
Early Outcome	**Text**	A comma separated list of the results of a patient scan
Treatment Cycle at Clinic		
Number of Foetal Sacs with Foetal Pulsation	**Number**	If foetal sacs were present in the scan, the number of sacs that evidenced foetal pulsation
1st Foetal Heart - Weeks Gestation	**Number**	The number of weeks of gestation for this foetal heart, banded if less that 30 or greater than 40 weeks
1st Foetal Heart - Birth Outcome	**Text**	Comma separated list of the outcome of this pregnancy
1st Foetal Heart - Birth Weight	**Text**	Banded birthweight of this child
1st Foetal Heart - Sex	**Text**	The sex of this child - M if male, F if female
1st Foetal Heart - Delivery Date	**Date**	The year this child was delivered
1st Foetal Heart - Birth Congenital Abnormalities	**Bit**	1 if a congentital abnormailty was recorded, 0 if not
2nd Foetal Heart - Weeks Gestation	**Number**	The number of weeks of gestation for this foetal heart, banded if less that 30 or greater than 40 weeks
2nd Foetal Heart - Birth Outcome	**Text**	Comma separated list of the outcome of this pregnancy
2nd Foetal Heart - Birth Weight	**Text**	Banded birthweight of this child
2nd Foetal Heart - Sex	**Text**	The sex of this child - M if male, F if female
2n Foetal Heart - Delivery Date	**Date**	The year this child was delivered
2nd Foetal Heart - Birth Congenital Abnormalities	**Bit**	1 if a congentital abnormailty was recorded, 0 if not
3rd Foetal Heart - Weeks Gestation	**Number**	The number of weeks of gestation for this foetal heart, banded if less that 30 or greater than 40 weeks
3rd Foetal Heart - Birth Outcome	**Text**	Comma separated list of the outcome of this pregnancy
3rd Foetal Heart - Birth Weight	**Text**	Banded birthweight of this child
3rd Foetal Heart - Sex	**Text**	The sex of this child - M if male, F if female
3rd Foetal Heart - Delivery Date	**Date**	The year this child was delivered
3rd Foetal Heart - Birth Congenital Abnormalities	**Bit**	1 if a congentital abnormailty was recorded, 0 if not
4th Foetal Heart - Weeks Gestation	**Number**	The number of weeks of gestation for this foetal heart, banded if less that 30 or greater than 40 weeks
4th Foetal Heart - Birth Outcome	**Text**	Comma separated list of the outcome of this pregnancy

4th Foetal Heart - Birth Weight	**Text**	Banded birthweight of this child
4th Foetal Heart - Sex	**Text**	The sex of this child - M if male, F if female
4th Foetal Heart - Delivery Date	**Date**	The year this child was delivered
4th Foetal Heart - Birth Congenital Abnormalities	**Bit**	1 if a congentital abnormailty was recorded, 0 if not